## Bridge to Survivorship: A Conversation with Devan Voight,

## WVU Cancer Institute Chaplain

Lauren Hixenbaugh (00:01):

Welcome to Living Beyond Cancer, this is a series of podcasts created for cancer patients', survivors, and their caregivers. Hi I'm Lauren Hixenbaugh a Program Manager for mobile cancer screening at the WVU Cancer Institute and I'm a host for today's episode and I'd like to introduce my co-host Andi Hasley.

## Andi Hasley (<u>00:11</u>):

Welcome everyone I'm Andi in addition to being the Mountains of Hope Coalition Manager I'm a breast cancer survivor as well. Living Beyond Cancer sponsored by the West Virginia Cancer Coalition Mountains of Hope and is produced by WVU Cancer Institute's Cancer Prevention and Control, we are thrilled to share today's episode with our listeners. Thank you to Devan for joining us today. We're really excited to have you. I just wanted to share with listeners before we start that Devan and I actually met beforehand as patient to advisor. If you listen to my episode of the podcast, my cancer story, and just sharing transparently with our listeners, sometimes I have to get the Andi's cancer story out of the way before I go into Andi's work story. So Devan and I met beforehand, and we spoke a lot about finding meaning in a diagnosis and in the after diagnosis and in the survivorship. So Devan, could you share, what do you mean by that finding new meaning and making meaning?

## Devan Voight (<u>00:51</u>):

Certainly, and thank you as well for having on here. And I did very much enjoy getting to meet you and have that personable one-on-one, face to face. And yeah, we talked a lot about what does it look like and what does it mean to find meaning, especially in the middle of a diagnosis. I think that finding meaning is something that we do naturally. I think it's something that comes just naturally within us to want to understand things, and a lot of times finding meaning answers that question why. It helps us to understand what's going on. And when we get a difficult diagnosis, specifically if we find out that we have a cancer diagnosis of some kind, that disrupts our life. That, for lack of a better word, kind of throws a wrench in our plans and everything that we have anticipated life to be and things moving forward. And so when that happens, I believe that it doesn't only disrupt those plans, but it kind of disrupts that sense of meaning or fulfillment we have in life, the way that we understand life to be.

## Andi Hasley (<u>02:09</u>):

One of the things that you and I talked about is the whole, it's not supposed to be this way, I wasn't supposed to be diagnosed with cancer when my kids are young, or I wasn't supposed to have to take care of my parents at a younger age. How do you help people find that meaning and then apply it into the next steps of the diagnosis.

Devan Voight (<u>02:37</u>):

Traumatic experiences often disrupt that feeling of meaning, that sense of meaning that we have. I think that process to redefine it or to rediscover it is not an overnight thing. It's something that takes a very long time. And I personally think that meaning itself is something that's a lifelong process because things change and we adapt to those changes. And one of the ways that I make meaning through adapting to changes is that, that kind of equips us for the next stages of life or that makes us stronger. And being able to be with people as they're in that process, I think just that itself is part of the help, is to be able to connect with somebody else, to be able to have someone who cares to listen to your story and where you're at and not try and immediately push and pull you one way or the other.

# Devan Voight (03:33):

Because I think that rediscovering meaning first starts with that awareness that there has been a disconnect or there has been some disruption. And once we have that awareness, then we can do something about it, but we kind of have to allow ourselves some openness and honesty and vulnerability to get to that point. I think one way that I've been able to be with patients as they've worked to rediscover their meaning again is to just in a very non-judgmental way, listen to them.

## Devan Voight (<u>04:08</u>):

I'm recalling a patient who I saw a few months back and she was getting ready to enter into retirement. She had all of these plans of how to spend time with her grandchildren, what she was going to do, vacations that she had planned, things she was going to do with her spouse and her kids. I mean, the list went on and on, and then she just didn't feel well. Eventually, someone had suggested to go get checked up and she went into the doctor's office not ready for... Essentially, she went in thinking that she was going to walk right back out, but instead the opposite happened. She went and sat down. They drew labs and told her that they needed to get her into the emergency room, and then eventually inpatient. She found out that way that she had cancer and everything changed. And so all of those plans, those hopes, those dreams were in that very moments in her words, they were kind of crushed.

## Devan Voight (05:11):

So I believe to be able to sit with someone in the midst of that and to hold that with them is I think one of the beginning steps to that discovering meaning process. A recognition that the meaning has been disrupted or that there has been a loss, and with that often comes grief too that has to be acknowledged and has to be worked through.

## Lauren Hixenbaugh (05:35):

And with that, I was kind of thinking, we hear a lot of our guests say that they couldn't handle anymore or they didn't think they could handle anymore, and somehow every time, they do. That comes from them just taking the next step, whatever it is, just focusing on, okay, I've got to get to part B, C, D E. I know that you and Andi had talked a little bit about that in kind of training yourself to find meaning and how we get to that next step.

## Devan Voight (<u>06:06</u>):

Yeah. I think when we work to train ourselves to find meaning it's kind of like any exercise, right? We're rusty at first, where like I think of myself when I'm getting back into the gym, I'm

sore, I'm achy, I'm winded a little bit more easily. And so it takes time to kind of build that up. But one of the first steps that I think we have to engage in that process is a sense of curiosity.

## Devan Voight (<u>06:33</u>):

Albert Einstein in an interview had a reporter ask him a question about, "If you had one piece of advice to give to my son," because the reporter's son was with him, "what would it be?" And Albert Einstein sat thoughtfully for a moment and then said, "Never lose a holy curiosity." And so to embrace the curiosity and to really allow yourself that space to dig into it, to explore what newness is out there, what are some new ways that we ourselves can become agile in a way to kind of rediscover the things in life that give us meaning or how to hold onto those things, but just approach them differently.

## Devan Voight (<u>07:19</u>):

With the woman I was talking about earlier, that visit that I had talked about that was early on in her diagnosis. Not too long ago, I met with her again and from where she was then to where she is roughly now, she is in a space where she's finding how to incorporate her grandchildren in her treatment, how to make those days, days where she can spend with them or after treatment, as long as she's feeling well, go and see them. And it's not what she had planned, but she's kind of arrived at a space where for now it'll do, that this is only temporary and eventually she can return to what I would call, a new normal.

## Andi Hasley (<u>08:06</u>):

So how then, and you might not even know the answer to this, but how did she get there? What was her process of going from, this isn't how it was supposed to be to almost, it sounds like, acceptance. What did that look like?

# Lauren Hixenbaugh (<u>08:29</u>):

Well, I kind of wonder if that goes back to what you said about finding new meaning. It seems like maybe it's kind of a combo there.

## Devan Voight (<u>08:37</u>):

Yeah. I think it is a bit of a combination of both because we have to... Like when meaning is disrupted, there's grief. I don't think that we can move past that without acknowledging the grief and allowing ourselves permission to engage it. And that grief might involve crying, it might involve anger, it might involve having people sit around and just talking about it and sharing stories about it. But we have to confront that, I think, and hopefully we confront it in a healthy way to then find a point of acceptance.

## Devan Voight (<u>09:12</u>):

I think for her, and I think what's helpful for a lot of us to do is to ask ourselves, what matters most to us? Because often the things that matter most to us are the things that we're going to really find meaning in. Maybe that is your work for you, maybe it's your family, your friends, a hobby you have. Maybe you're very artistic, and so you write poetry or create songs or visual art, whatever that might be. And so to identify what matters to us, and then we can ask ourselves,

how can we still engage that? And so for her grandchildren were people who were super important in her life. And so for her to be able to engage... What am I trying to say?

## Lauren Hixenbaugh (10:03):

Well, I was just going to comment about how beautiful I think that it is, that we can each handle something like this and pull new meaning from it. And it's okay that we all deal with it in a different way, because there's no wrong way for us to deal with it, right? We can be angry. Some people deal with it with humor. Some people are sad, and it's okay however we need to handle it, pull meaning from it one way or another, as long as we find ourselves on the other side eventually.

## Devan Voight (<u>10:34</u>):

Yeah, and I think that can be the difficulty, right? Because that goes back to being very open and honest and vulnerable with yourself, which I think we naturally struggle with because a lot of the times that involves showing parts of ourselves that we don't want to, even if it's all just showing that part of ourselves to ourselves. But I think of a lot of Brené Brown's work is really connected to vulnerability, and being open, and that there's courage in that.

## Devan Voight (<u>11:02</u>):

And when we can be vulnerable, then we can acknowledge it, we can develop that awareness, and then we can start to look for that new normal. Because illness takes a lot away from us, cancer takes a lot away. And whenever there's a loss of something, I believe there's something to be grieved. And so we can't step into that new normal, or that newness or that new sense of meaning without first dealing with the grief that comes with it.

## Andi Hasley (<u>11:32</u>):

So then when we're talking about this, we're just talking about there's immense change that happens from that kind of diagnosis and it's constant change. I think that a lot of people think that you go through the action part of a diagnosis, you know, diagnosis, surgery, treatment, whatever is involved, and then there's a period at the end of that sentence, but that's not at all the end of the healing. So what is the balance between kind of getting back to the new normal of what life looks like now, being independent and staying connected, or I guess rediscovering the connection that you have with your loved ones, your friends, your coworkers? What's the secret recipe in that, I guess would be the question.

# Lauren Hixenbaugh (<u>12:26</u>):

Well, and where can it be found? Who should be rope in for that journey?

## Devan Voight (<u>12:37</u>):

I would love to be able to give the perfect answer to that. But honestly, I think it's such a moving target for everyone. To your point, Andi, about that a lot of times people anticipate there being a period and it ends, and then that realization that it doesn't, that can prolong that difficulty. Because then the questions and concerns are there of, what if this isn't the end? What if it comes back in a year, two years, six years? And unfortunately, that's happened. That's happened to a lot

of people. And so it is kind of this constant just willingness and ability to adjust to what's going on. Can you ask the other part again?

## Lauren Hixenbaugh (<u>13:22</u>):

I just want to make sure that we address, as we're talking about meaning and where to find it, that we give people a place to go. Who should they talk to about this and where to find those people?

## Devan Voight (<u>13:37</u>):

Sorry, I think because Andi had said something about individuality versus community, and then where do you go to find that? Right? Okay. That's another balance to walk there because I think too much individuality can lead to isolation, and then too much community can lead to a loss of your sense of self. And so you have to find that balance of, where do you carve out time for you? What are the activities that energize you and recharge you? And what are the ways that you can be around people that is also fulfilling in that way? And I think that a lot of people, as far as on that community side of it, find a lot of help and meaning in just spending time with family and friends. I think that they find it in community groups as well. If that is some type of a sports group that you participate in or intramural, certainly church is a big one.

## Devan Voight (<u>14:41</u>):

I know for me personally, church is one of my main areas for community. To be involved there and to be around people who care about you, want to invest in you. I think too, being able to find, even if it's just one person that you trust, be that a therapist, a counselor, a close friend, whoever that might be, and to reach out to them and work through these challenges alongside of them. Because I find that, and I'm taking this from the psychiatrist, Irvin Yalom, but when we can find somebody else who is going through what we're going through or who isn't surprised at the difficulty of what we're going through, in his words, "We don't feel alone in our own wretchedness." We don't feel alone anymore, and that itself can be very healing.

## Lauren Hixenbaugh (<u>15:29</u>):

Absolutely. And I think Andi can speak to that as well.

## Andi Hasley (<u>15:33</u>):

Yeah. One of the struggles for me in ending up in this career was taking the time to lay my diagnosis aside sometimes because it is my job. However, I also work with people that literally work in that diagnosis and they don't even question if I'm having a bad day. Not only are they resources, but they're usually equally irritated that I'm having a bad day because they live in this world all the time. I thought it would be harder for me mentally, but it's actually not. It's the reverse.

## Andi Hasley (<u>16:10</u>):

And you mentioned a sports team. My son, the other day, he's 11, I was taking him to flag football practice and he says to me, and you know, he's 11, so you just never know what's going to come out of his mouth. And he says to me, "How would you feel about a tattoo?" I was like, "For me?" And he goes, "No, like when I could get a tattoo someday." I said, "Well, you would be 18 before you can get a tattoo." And he said, "Well, I mean, would it be weird if I got a breast

cancer ribbon?" And I said, "Well, no, but I mean, you could get whatever." And he goes, "Well, I mean, I'd like a tattoo that means something." And then he said, "Plus I think that it would be nice for me to remember it for people to see, you know, that we got through it." And I thought, wow! Out of the mouths of babes, here's this, my kiddo that... Like, he processes it in a way that could be public.

## Andi Hasley (<u>17:14</u>):

I thought that was really interesting that you talk about sports teams because he thinks about it in those contexts in related to our own journey. Some teams during October didn't do the pink thing, and he thought that, that was terrible. He was like, "I'm not cheering for those teams because they're not... Their cheerleaders don't have pink pom poms." I was like, "It's really okay. I bet they're doing other things. It's fine." But that rally of community, which is kind of what you're talking about is really part of the journey, but some people struggle with that. Some people really want to not remember any of it. They just want it to be over and done and not have a reminder of this. I know that, that's something you and I have talked about, but do you have any thoughts on what that looks like as far as navigating it with people that just want it to be over and done?

## Devan Voight (<u>18:12</u>):

Yeah. I mean, to what Lauren was saying earlier, there's not necessarily a right or wrong way to do this. It's not black and white, it's just a number of shades of gray. I think that, that's a normal response. At least to me, it sounds like a normal response to want it to be over with because it's this inconvenience, and I think that's putting it very lightly. And so we want it to be completely out of the way.

## Devan Voight (<u>18:41</u>):

My mother and on my mother's side of the family, and Andi and I had talked about this a little bit too when we had met, has the BRCA2 gene, and I have inherited that as well. There are a lot of things about that, that our family has experienced it. I mean, I would love for it just to be gone. If it could just disappear one day, that would be fantastic. And in some ways, it doesn't erase the damage that's already been done and some of the lives that have been lost on my mother's side of the family, and yet there's that desire again, of just, we want it to be over with.

## Devan Voight (19:19):

But looking at how my mother has dealt with it and getting a double mastectomy and having reconstructive surgery, and then the complications that came with that, that 10 years down the road, she finally feels like she's on the other side and is feeling better, but I mean, that's a 10-year journey in itself. And there were all sorts of complications. And I know for periods of time, my mom just wanted it to be over with and done. But I think as my mom started to find things that were enjoyable for her, joy was introduced into her life again. She found purpose and meaning in gardening and in taking care of her pets. And eventually, getting more outside and getting around friends and family again. And so that was a process for her to get to that point, but once she was able to, she kind of challenged herself with that. And I can look at where she is now versus where she was then, and she's so much happier and she seems so much more fulfilled and more like the mom that I knew prior to that news coming through.

## Lauren Hixenbaugh (20:33):

And I'm going to do a little bit of a shameless plug here for our listeners, because you touched on something with your mom's care that I think is important, which is you talked about her gardening and getting back outside and being able to be a little more active. And we did kind of cover physical therapy for folks that were survivors and kind of getting them back out, and people do find meaning in that and joy, and that is a huge part of their recovery. And so I encourage listeners to go back and listen to that physical therapy podcast that we recorded and listen to that if they're struggling with those parts of their survivorship care.

Devan Voight (<u>21:11</u>):

Yeah, it's wild. Oh, sorry.

# Andi Hasley (21:13):

And to add to that, sorry, Devan, it really works. I am here to tell you as a person that has experienced it myself, it really, really works. And it's not anything that... I think sometimes we feel like we have to move mountains for it, but we really don't. I mean, it can be something as simple... I mean, I have right here next to me, I'll show you on the screen. I have my stretch bands that came from physical therapy and I have three different colors and they're three different exercises. I do them in between Zoom meetings, or I get up and... It's really simple. So I think sometimes when people think of things physical, they think it has to be this Herculean effort, and it's really not at all. We talked before, but I'm so glad that your mom is finally turning the corner on it because 10 years is a long time. That's frustrating to think in decades of healing. That's tough. So I'm glad that she's finally finding some joy and moving on to the next step.

## Devan Voight (<u>22:19</u>):

Thank you. I am too. Just to what you all were saying about just getting outside or finding ways to be active, it's wild, the connection between our mind and body. I believe, again, coming from my point of view, our mind body and spirit are interconnected. And so if one's suffering, the other two can tend to kind of fall down with it. But if we find ways of like, let's just say meditative practices, to practice breathing and sitting in silence and just kind of allowing ourselves to be, and be attentive to ourselves, that can have profound impacts on all other sides of our lives just as getting outside and being active, walking, stretching, running, lifting, using your bands. I don't know, to me, I've always found it very fascinating how that works. And yet that can be another way that we get ourselves back out there or we find things that can help pick us up when we're feeling down.

## Lauren Hixenbaugh (23:26):

So that kind of brings us to our next topic, which is for those folks that aren't spiritually minded, what would your advice be to them? What could we kind of address here in this podcast for those folks?

## Devan Voight (23:41):

Yeah, yeah. To the point of meditation, even though meditation itself is rooted in a lot of spirituality from all across a variety of religions and philosophies, I think it itself has a lot of practical benefits as well. And even now a lot of companies are, and I think WVU has one as

well for like mindfulness programs. And so finding ways to engage mindfulness can be very helpful for that. And I've found in a lot of those spaces that they help me to be reflective on myself. I think too of, you know, how, even though that these philosophies and religions and other things point towards finding purpose, again, I think that's very universal.

# Devan Voight (<u>24:34</u>):

And one way that I look at it that I think can kind of fit... I can't think of the term. I don't want to say one size fits all, because I feel like that's a little... Not what I'm looking for, but I think a lot about stoicism. That's a philosophy that is very much on focusing on our own introspection as humans and the human experience and how to acknowledge the things that hinder us, how to acknowledge the things that don't, and where to find purpose within that.

# Devan Voight (<u>25:17</u>):

Epictetus was a stoic philosopher who, in reflecting on Hercules, had said, had Hercules not encountered the Hydra or the lion, all of these challenges, Hercules wouldn't be the person that we remember now. It wouldn't be this legend. And another way that I can think of that is the statement that "smooth seas don't make for good sailors." The struggles that we face in life, the really, really difficult griefs that we carry, I think shape us and help us kind of grow as people. And that's not an easy statement to say, and that's not a pretty statement to say either, because again, we have to acknowledge what grief does to us, especially when we're looking at a cancer diagnosis and just everything that, that entails.

# Devan Voight (26:13):

But I think of the hero's journey, and it's something that Joseph Campbell identified in reading stories all across just religious texts, work of fiction, non-fiction, et cetera, that there is this journey that people tend to go on and that has been applied to us. And whenever I've done patient groups, occasionally we've talked about that, and I found it to be very helpful and so have the people who've engaged it. And it's this idea that we find ourselves, the term they use is called "to an adventure", but I would say that we find ourselves in a pivotal moment of change. And when we cross that threshold of change, there are a number of challenges along the way.

# Devan Voight (26:58):

And often we don't have to face those challenges alone, we have, well, hopefully, have a community around us. We can have friends or support groups much like this one that we can engage and help us through those challenges. And as we face them, we grow and we kind of enter into this transformative stage that can sometimes feel like this death and rebirth of our old self to our new self. And again, if I were to look at my mother again and look at where she was then versus now, there very much has been this rebirth or this transition from how she was in her early and middle stages versus where she is now. Much happier, feeling much healthier, a higher appreciation of life. And I think those are perspectives that we gain when we find ourselves in the midst of suffering and facing that. And ultimately, the hope in the hero's journey is that we come out the other side and we come out changed and better equipped for whatever the future holds.

# Lauren Hixenbaugh (<u>28:07</u>):

And I do think we hear that a lot with people we've interviewed is that they had a piece of themselves that they had to say goodbye to. There's some form of grief there that I will never be that person I was before cancer. And it doesn't necessarily mean that one is that was the good life and this is the worst life or one way or another, right? It's just, how do we find meaning and growth and become a better different version of ourself than we were before and kind of how we move through that. I mean, I think that's kind of what you're talking about. What's the adage? Something about, it's not the destination, it's the journey. That's kind of what we're talking about.

## Andi Hasley (28:56):

Well, and I really like when you talk about that is you don't use the word acceptance as part of it. Because I think to me, the word acceptance is like a finality of something, whereas returning means that it really is a cycle, that there's movement, and then there continues to be movement past that. Because I think that accepting a cancer diagnosis and the long term of it, at least for me and my current journey, almost feels like you're waving the white flag, and that's not how I feel. I feel like, okay, well, here we are, what is the next thing that I need to do? And so I like that it's a cycle versus an end. That's really good.

## Devan Voight (<u>29:50</u>):

I hadn't thought of it from that perspective of how acceptance can, in some ways, kind of produce that sense of finality versus, like you're saying, that idea of a cycle of you're constantly growing, you're constantly moving, there's progression. And hopefully, it's progression in a healthy way or a better way, whatever that might look like.

## Lauren Hixenbaugh (30:13):

And kind of continuing with this. So as we talk about different ways people can think about their journey, what for you has been the biggest challenge from an emotional support standpoint? Like when you're helping folks, what has been the biggest challenge for you?

## Devan Voight (<u>30:40</u>):

So I think for me, one of the bigger challenges that I've faced is the grief that does come with the work. I mean, there's joy there too, there's purpose there, I do find meaning in this work, again. And so for me having a sense of meaning and purpose in this is one of those things that helps me to continue engaging it, even through all the grief, but the grief is there. And particularly when I'm with people for quite a long period of time, months, a year, however long it might be, and they continue to decline in ways, I guess you could say, and they're just not feeling well, then as time goes on, you can see sometimes that hope start to go away. That's a hard thing to witness. But I think for me to be there in those moments too, and to be willing to engage, that there's something meaningful that happens there.

## Devan Voight (<u>31:53</u>):

And I think of the Pixar movie Inside Out when Joy and Sadness are separated from the rest and they find the imaginary friend whose name I can't remember right now, and he loses his makebelieve rocket ship and Joy is trying to just cheer him up and get him back on his feet and pull him along and he's just not budging. And so Sadness comes and just sits with him and acknowledges the grief, and he has space at that point to voice it, to cry. And then it's after that he's able to get back up and say, "Okay, I've acknowledged the grief, I've engaged it, I'm ready to continue towards the next part." And so I think that's where there's a necessity of being willing to sit in the grief with people when it's there. But it's hard to witness that, especially as it progresses towards or when it has progressed towards end of life.

# Lauren Hixenbaugh (<u>33:07</u>):

And I just want to clarify, because I actually don't know. I mean, I have a general understanding of what your role is, but I feel like maybe this would be a good time to talk about what exactly is your role as you're helping these folks. Are you helping just the individual that is the cancer survivor, the family? What type of services are you coordinating? That sort of thing. And I'm asking for our general audiences and who they should ask for if they feel like they would need some assistance.

# Devan Voight (<u>33:43</u>):

Yeah. So it's primarily spiritual and emotional support. And the reason we make that distinction is to, which you said earlier, Lauren, not everybody considers themselves spiritual, but I believe everybody is emotional. We all have emotions, we experience them. And whenever we're in the hospital, dealing with illness, I think our emotions are very much involved and touched by that. And so what myself and the other chaplains do is we make ourselves available to be there, to help people, or rather to create space for people to process through those, to help try and find ways to connect people to their faith or spirituality, if they have that, to find ways to connect people to others and resources.

# Devan Voight (34:36):

One thing that I love doing is patient support groups, where I always kind of express that my intention in this is that we can all come out better connected to each other, ourselves, and our higher power. And so again, that connection is kind of interwoven through all of it, and it's because I believe that when we are alone in our isolation, we feel cut off. But when we can experience meaningful connection, that to me, I believe is life giving. And so sometimes, you know, some of the best patient encounters I have had have been when I've said absolutely nothing. And I've walked in, I've introduced myself, and I have just sat with someone for an hour or so as they share their story and just have someone who listens and who cares.

# Devan Voight (<u>35:34</u>):

On the other side of it, sometimes too, patients are in a different space than their family are. And so to be able to recognize that and to either work to create a space where both can kind of openly process that together, or to kind of recognize, maybe we need to step aside and spend time, you know, myself with the patient and then myself with their family or friends to have that opportunity. And one time that I had done that, one of the patients here was really starting to contemplate her mortality, and her family didn't like hearing that.

# Devan Voight (36:12):

So for me to be able to acknowledge that and sit down with just them and give them space to process through it, and all they wanted to do was to plan their funeral. And I had worked in a funeral home before, so I had some knowledge about that stuff. And so we were able to sit down

just the two of us and offer her an experience that she hadn't had elsewhere. To walk through that and ask those questions and really think through what that's like. And in doing so, it kind of helped her to also open up and talk about her own concerns for that as well as a sense of peace that she had found in it too. I recognize that was a very lengthy answer to your question.

# Lauren Hixenbaugh (36:51):

No, you have a really difficult job. I know there's some joys as well, but you have a really difficult job. And I think meeting people where they're at and respecting them and their wishes and their journey is really difficult for family and friends. And so I think it's wonderful that they have an opportunity to meet with you and be able to kind of be more patient centered, that they can choose what they want to do and not what their family wants them to do, or even what their family wants to hear or talk about. That's wonderful that you're able to provide them with that support.

## Devan Voight (<u>37:30</u>):

Well, Thank you.

# Lauren Hixenbaugh (<u>37:31</u>):

One other thing that I wanted to tap on to the end of that, and I believe you had talked about it previously. I always like to talk about people advocating for themselves, and this is just another form of them advocating for what they want. And it's so, so important throughout the entire cancer continuum to be able to advocate for yourself and end of life care is no different. I think that's important for people to understand, but being able to advocate for what you want, even with end of life in mind is really important.

## Andi Hasley (<u>38:03</u>):

It's very interesting. When you talk about the balance between the family's wishes, the patient's wishes, how sometimes they're very different, and then not only are you a resource to sort of help the patient advocate for themselves, but also in helping their family find acknowledgement in the patient's choice. So could you share a little bit about how you do that?

## Devan Voight (<u>38:42</u>):

Yeah, I think it takes a lot of recognition of where the patient and where the family is at. There are a lot of times where I have experienced patients say one thing, maybe just a statement like, "I'm really tired, and I'm starting to rethink what this looks like for me, what treatment looks like for me." And then when they get around their family, that attitude kind of changes, and the statements are very different of, that fight mentality kind of comes out. And I try not to push too much on the fight mentality because when people do start to feel tired, I find it sad when it feels like you're giving up. I think sometimes it's a sense of, you're reevaluating where you're at and what you want out of life, and maybe you want the remainder of your life to look a certain way. And again, the reason that I talk a lot about this finality or mortality is because those are cases or situations where I find myself involved a good bit of the time.

# Andi Hasley (<u>39:59</u>):

Well, I'm sure that the patients, especially if it's parent to child, they don't want their kids to worry. I think that's a big part. I mean, I was like that and my cancer was not terminal. I just didn't want my kids to worry. I just wanted to pretend like, "Oh no, I'm good. I've got this." And in a terminal situation, I would imagine that it would be difficult to be able to be honest with your family because then you know they're going to worry and you don't want to make it harder on them than it's already going to be.

## Andi Hasley (<u>40:43</u>):

So yeah, it's tough stuff. I'm very grateful for people like you who really are able to be a neutral party, for lack of a better word. You're involved emotionally obviously, but you're able to do it in a way that is professional and trained and not react with your heart only. And I think that might sound harsh, but it's very needed when you're helping someone advocate for their choices.

## Devan Voight (41:21):

And I can say from my own experience with what my mother went through, she didn't like to share a lot of that, or at least I never heard a lot of it because I think, like you're saying, that parent-child dynamic, she didn't want me or my sister to worry. So if you can keep some of that tucked away, I think you create that zone of worrilessness, I guess we can call it. But I think that does damage to us when we don't address it because we stuff it down and it builds and builds and builds.

## Devan Voight (<u>42:00</u>):

And I think, Andi, you and I had talked about this last time, it was like at some point it's going to come out and the term they will use is it comes out sideways. It's going to come out whether you like it or not, and it might be in a way you don't want it towards a person who maybe you don't want it to come out to, or you didn't deserve to come out to, whatever that might be. And so to find ways to address it, even if it is, again, just finding your person to talk through it with, just someone you can be very open and honest in yourself with.

## Andi Hasley (<u>42:32</u>):

As I mentioned at the beginning of the podcast, Devan and I met in advance, so that Andi, the cancer patient would not be Andi, the cancer patient necessarily on this episode. One of the things I talked to him about was that I'm just angry a lot, like I just get mad and he says to me, "What has helped you deal with this?" And I was like, "I don't know." And so he shared a lot of things when I said that, that I felt that our listeners and their caregivers would really benefit from hearing. So Devan, would you share a little bit about that with our listeners?

#### Devan Voight (<u>43:13</u>):

Sure. So I think when we feel a certain way, it's natural for us to feel that way. And I know for me, when I'm feeling some kind of way, it's hard for me to step back and ask myself like, "All right, what am I going to do about this?" Because I'm caught up in the moment, I'm caught up in how I'm feeling. And sometimes, whether it's selfish of me or whether it's appropriate of me, I don't want to step away from that, and I don't think that we can do that indefinitely. I think at some point, we do have to find ways to address that.

## Devan Voight (<u>43:47</u>):

And so one of the things that I have said a few times already, it's that awareness, we have to be aware of how we're feeling. And if we can be aware of how we're feeling, I think the next step of that is, what is causing that? And that can sometimes be a harder part or at least for me, it is. But I know too, for some people, it is hard to identify how you're feeling. There are things that can stand in the way of that. And so to be able to get to a point where you can say, "X is making me feel Y." Then I think it can be addressed, which comes to the next step of more work. It's nothing but work, but I think it's healthy self work for us to do.

## Andi Hasley (<u>44:33</u>):

So when you talked to me, tell them the boulder analogy, because it made sense to me and nobody had ever put it that way before, and I think that there's other people out there will also go, wow!

# Devan Voight (<u>44:51</u>):

If I remember correctly, I think it was the coyote and road runner analogy, where we talked about how the coyote will have this big boulder or this massive pile of weight that's piling up, and then the road runner puts the little feather on it, and then that's the thing that caused it to crumble down. Of course, on the cartoon, it's very funny and humorous, and maybe in reality, you're like, "Well, how does the feather add that much more weight?" But I think when it comes to our emotions, in my experience, that's been the case.

## Devan Voight (45:24):

And a lot of people who I've talked to, I think have identified with it as well when we don't recognize and acknowledge our grief, our anger, our fear, our uncertainty, or whatever that thing might be, it grows. And the longer we go without addressing it, the heavier and weightier that boulder can get. And as it builds and builds, it's one of those things where eventually something very small can just cause that weight to become unbearable and just come crashing down, like when the coyote plummets. And when we come plummeting down again, that term that I've used, our feelings, our emotions, whatever that might be, can come out sideways towards or at other people. And so how do we find ways to address it, or for lack of a better term, to address the elephant in the room. I think that's the big question of once we've acknowledged it, once we know where it's coming from, once we've kind of accepted that it's okay for us to feel this way, then it's, how are you going to deal with it?

# Devan Voight (46:44):

And again, I don't think there's a wrong answer to that. If you're feeling upset and angry, and you have a lot of this build up energy inside of you, finding one of those rooms where you can break things can be a healthy outlet of that. Exercise can be another very healthy outlet of that, back to what Lauren was saying about physical therapy, finding a way to release it. If there's a lot of grief, then finding ways to acknowledge that grief. I've known people who have held little ceremonies to grieve parts of themselves that they no longer have. Someone recently held a little goodbye ritual for their hair when they ended up losing it. And so I think just to give yourself permission to be creative, or I should say to give ourselves permission to be creative with how we address that.

## Andi Hasley (<u>47:43</u>):

I think that when you do that, you're lightning the load. So you might not be able to put the whole boulder down, but maybe then if another feather comes along and you've lightened the load a little bit, it won't be the thing that knocks you over. And that I think is easier than we realize by just doing these little things. It doesn't have to be this gargantuan effort, it can be just one thing, and it lightens the load just enough. So that if something else comes along, because it will, it's life. I mean, it's life, there's always something. It doesn't have to just feel like the weight is continuing to push down. You're also relieving some of that weight too.

## Andi Hasley (<u>48:34</u>):

It really spoke to me, and it's not something that I had thought about before. And I actually came home and shared it with my husband and he goes, "Well, what did you say?" And I said, "I don't know." He goes, "Of course, you don't. Maybe we need to find something." So yeah, it actually stemmed a pretty good conversation in my household too, and has made me be a little more aware of the weight that I'm carrying sometimes unnecessarily, honestly. Just yeah, to get rid of my own boulder one little chip at a time.

#### Devan Voight (<u>49:10</u>):

And I think when we do that, we grow around it. There's an image of grief that I really like, and I found super helpful, and it's from Dr. Lois Tonkin who says that it's not that grief shrinks over time, it's not that this thing is going to just one day be minuscule and disappear, but rather we grow around it. We find ways to, like you were saying, Andi, to chip away at that boulder. And as we do, I think that, that equips us. Again, this is my own meaning making of this. It equips us to grow around that grief, so it becomes... I don't want to say easier to carry, but it's not as heavy for us to carry. The pain is going to be there, the loss is there, and we learn to continue on with it.

#### Lauren Hixenbaugh (50:08):

I like your analogy a lot, and I think it's important for people to think about the whole journey. Sometimes I know it's hard for people to... They're just such in the weeds that it's hard to think about the whole journey, and I really like the idea of people being able to grieve in the way they want to grieve. We talked a lot about finding meaning throughout parts of your journey, and we've talked about advocating, which I always think is really important again, throughout your entire journey. And then from a caregiver's point of view, like you said, asking people what they need is always important and kind of meeting them where they're at, which you're able to do that through your profession, which is amazing. And letting people tell you what they need. Sometimes they don't know, but I think it's really important that they're able to have a service like yours, that they can navigate through things themselves, but also with somebody so they're not feeling that loneliness. I think you've hit on a lot of really... Go ahead.

#### Andi Hasley (<u>51:14</u>):

No, you're good. And what you just said when you summarized it up, it made me think. All of those things that Lauren just said are those little tools to chip away at that big boulder, all of them are. I think sometimes we're afraid to ask if somebody has a tool to help us. We're afraid it makes us weak, we're afraid it makes us needy or an inconvenience. And the people that love us,

they are willing to get out their pitch forks and jackhammers and sledgehammers and help chip away that boulder, and people in your profession are very much available to do that.

## Andi Hasley (<u>51:59</u>):

So if there's somebody listening to this and you feel like the weight is just too heavy, Devan is there. He's got whatever tool that you maybe need him to help you chip that boulder. And if you're not in the general Morgantown area, there are folks in your area that do what Devan does. If you're not sure where to find those people, reach out to us and we can connect you with those resources too. The hardest thing for me personally was asking for help. And as soon as I did, the weight got a little lighter. So asking for help was a good thing.

## Lauren Hixenbaugh (52:43):

So Andi and I have kind of wrapped up our feelings on this episode, but I always like to bring it back to our guest and ask if there's one thing that our listeners were to remember from today's episode, what would you hope it would be?

## Devan Voight (<u>53:02</u>):

For me, I think it's a two parter. For the first part of it, again, I think it goes back to that courageous vulnerability and honesty that we can have with ourselves. If we can be honest about where we are in our own grieving process or where we are in our process, whatever that might be and how we're feeling, withhold judgment there, then we create a space for us where we can address that. And again, my thoughts through it is as we address it, we continue to grow in meaning and we continue to identify those things that are meaningful to us. And again, that can be whatever it looks like for you, whatever those activities or things or people are in your life that you find to be meaningful. But I think we have to address those things that stand in the way first that can often eclipse that.

# Devan Voight (<u>54:04</u>):

And then secondly, as I was thinking right before we started recording this, the quote came to my mind from a patient group that I had just the other week. And it's from Thomas Merton and he is an American, or he was an American monk writer, mystic poet, et cetera. And he had written the work, no one person is an island. To me, when I hear that, I hear that we don't have to be alone, and cancer can be very isolating, illness can be very isolating. And so challenging ourselves to not be that island, to recognize that we don't have to handle it alone and to look for those tools, those resources, those people that are out there. Just to connect it again with my family, one way that I saw my mom begin to heal was when she found a website or it was a Facebook group called the Pink Moon, I think, and the community there was very encouraging with her and it just helped her to start to engage that healing process. And she did so by finding community.

## Devan Voight (55:18):

She broke through that isolation chamber, connected with people who again, knew what she was going through, could connect and relate to her on that. And I know in the past, when I've dealt with the grief of losing someone I've loved, the grief of change and things like that, to find people who can connect with you on that, who can hear you and sit with you in the midst of that

can just be life changing because we don't have to do it alone, none of have to face anything alone, or at least I hope that no one would ever have to.

Andi Hasley (<u>55:55</u>):

Well, Devan, thank you so much for joining us today. You're doing amazing things for your patients and for their families. And we appreciate you giving us your time and sharing your experiences with our listeners. And we wish you continued success and luck in your work. And we're so excited to hear that your mom's doing well too.

Devan Voight (<u>56:24</u>):

Thank you all very much for having me on here. It's been a pleasure, and I look forward to just seeing what's in store.

Lauren Hixenbaugh (56:33):

Yes. Thank you so much. And we'll wrap up today with talking to our listeners about our Living Beyond Cancer Facebook page, which is available just by going to Facebook and searching, Living Beyond Cancer. And it's a really supportive community. We actually posted photos of Devan so that our listeners, as well as our folks in the support group could see that he was going to be here with us today and gave them an opportunity to ask questions. So please feel free to join that group. In that way, you can have some input on our upcoming speakers and working with us and asking them questions that could be answered on the next episodes of the podcast. Thanks again, Devan, we really appreciate you being here with us.

Andi Hasley (<u>57:21</u>): Thank you.

Devan Voight (<u>57:23</u>): It's my pleasure.